



Soula Mantalvanos published *Art and Chronic Pain – A Self Portrait*, to face her severe chronic pain.  
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## A phantom disease

**By Rachel Stern, MD**

Dr. Stern graduated in 2017 from Washington University in St. Louis School of Medicine. Her essay won Third Place in the Alpha Omega Alpha Honor Medical Society 2017 Helen H. Glaser Student Essay Competition.

“He had worked hard...only at forty to be vanquished by a causeless, nameless, untreatable phantom disease. It wasn’t leukemia or lupus or diabetes, it wasn’t multiple sclerosis...it was nothing. Yet to nothing he was losing his confidence, his sanity, and his self-respect.”<sup>1</sup>

This is how Philip Roth’s novel *The Anatomy Lesson* begins. Once a prolific and controversial writer, the narrator, Zuckerman (largely assumed to be Roth’s alter-ego), is now reduced to lying on the floor with a bottle of vodka and an orthopedic pillow, nursing unbearable back pain. He visits a multitude of doctors who regale him with emollients, pill cocktails, physical therapy regimens, and advice to address his unconscious, spiritual unrest causing physical discomfort. Zuckerman tries to eliminate his pain with some soul-searching, but as a writer whose career has been built on plumbing the depths of his id for artistic material, he cannot find an

unexplored hostility or childhood trauma whose repression may be leading to his chronic pain. “His unconscious wasn’t that unconscious. Wasn’t that conventional.”<sup>1</sup>

Failing to find a physiologic explanation for his pain, and unable to write effectively in an opioid haze, Zuckerman decides that his only recourse is to become a doctor. He does not anticipate finding a cure to his physical pain, but rather achieving relief through a sort of spiritual redemption, the kind that he expects only doctors have access to. “After the popular triumph of his devilish act of aggression,” that is writing, he will attempt the “penitential act of submission,” that is healing.<sup>1</sup>

To Zuckerman, medicine is as straightforward and morally clear as writing is messy and morally ambiguous. “A leads to B and B leads to C. You know when you’re right and you know when you’re wrong.”<sup>1</sup>

Zuckerman’s planned transition from invalid and writer to doctor contrasts with the journeys, as chronicled in their memoirs, of people who turn to literature and writing to gain relief or clarity. In *Body Undone: Living On after Great Pain*, a memoir of chronic pain and paralysis following a bicycle accident, Christina Crosby, a professor at Wesleyan University, draws from various poets. The eponymous line comes from Emily Dickinson’s “After Great Pain,” setting the stage for the timelessness of the chronic pain that will define the rest of her life.

After great pain, a formal feeling comes—  
The Nerves sit ceremonious, like Tombs—  
The stiff Heart questions “was it He, that bore,”  
And Yesterday, or Centuries before?<sup>2</sup>

Crosby is not alone in her quest to make sense of pain through literature. Hilary Mantel, the author of *Wolf Hall*, writes about her chronic pain and infertility from endometriosis with an extended metaphor of ghosts representing the children she never had, the person she could have been. John Milton’s *Paradise Lost* serves as the structure through which Lyne Greenberg, an English Professor at Hunter College, explains her debilitating headaches in *Body Broken: A Memoir*. While these authors find a way of shaping their amorphous and elusive experiences of pain

through their own writing, there is no concluding sense of salvation or healing.

Writing and literature are ways of facing the pain, sharing the burden, but not transcending it. The pain these authors suffer is more than chronic; it is eternal. Viewing their day-to-day lives as an eternity of suffering makes more sense through the lens of the horror genre than inspirational literature. Crosby concludes her memoir with a parallel between her life and Edgar Allan Poe’s *The Fall of the House of Usher*, “I’m not writing a horror story, I’m living one.”<sup>2</sup>

Mantel’s ghosts are not exorcised in triumph, but become accepted as her constant companions. Ghost children, she thinks, “don’t age so they don’t know it’s time to leave home.”<sup>3</sup> She continues to be haunted by her alternative life, the one in which she is pain-free. “Mourning is not quick; when there is no body to bury, mourning is not final.”<sup>3</sup>

Greenberg uses Milton’s description of hell to describe her new reality with chronic pain, an eternity of archetypal proportions:

Regions of sorrow, doleful shades, where peace  
And rest can never dwell, hope never comes  
That comes to all; but torture without end.<sup>4</sup>

Rather than overcoming their pain, these authors are simply trying to make their lives liveable, to give their pain, which has disrupted their sense of reality, a cohesive narrative. One way of doing so is to chronicle the parallel world they now inhabit, where the horrific is mundane.

### Accidental perpetrators

For doctors, turning the horrific into the mundane is not a widely acceptable goal. Doctors are often accidental perpetrators of misery as they try to use their well-known procedures to fix a little-understood symptom. More so than many other illnesses, chronic pain remains a mysterious condition that frequently fails to respond to the best treatments.

Greenberg writes, one in five Americans suffer from chronic pain, and even after significant pain management

intervention only 50 percent are functional enough to resume working. Knowledge, technical skill, empathy, and experience are not enough to bring these authors back to their former selves.

Crosby writes poignantly of how the enterprise is doomed from the moment she is asked to rank her pain on a scale from one to 10, an absurd metonym for her “electrified neoprene skin.”<sup>2</sup> She doesn’t blame doctors for failing to communicate; the experience of pain defies communication, adding yet another dimension of suffering and loneliness.

Even writing cannot adequately express the sensations of pain Crosby is experiencing. She tries with various metaphors and adjectives, but concludes, as others have before her, that rhetorical tricks are inadequate. “I’ve learned that the recourse to analogy is not solely mine, since pain is so singular that evades description, so isolating because it’s in your body alone.”<sup>2</sup>

### Making it personal

As someone with an enduring faith in the power of the written word, its failure affords a special pang. I turned away from writing towards medicine, as Zuckerman did, because I also longed for a “penitential act of submission,” a way of overcoming an all-consuming uneasiness at facing a life without concrete purpose. A vague sense that, in becoming a doctor, I would transcend the prosaic suffering of what Macbeth famously called “the petty pace from day to day.”<sup>5</sup>

Setting a broken bone, administering antibiotics, removing an appendix, the purposefulness of these actions were beacons of clarity in my swirling, anxious mind. Encountering the phantom of pain in both my personal and professional life has solidified what four years of medical school had already intimated. In medicine, A does not necessarily lead to B, and the nature of B is frequently questionable.

Reading these memoirs reminded me of the way in which writing can help where medicine falters. While words proved inadequate in describing Crosby’s experience, they did give shape and structure to what would otherwise threaten to overwhelm any personal identity. A horror story is still a story, and its characters are still their own entities:

If I am myself, what the hell  
who the hell is this body...If I can show you, perhaps I’ll  
be able to see too<sup>2</sup>

Mantel describes a similar effort:

I am writing in order to take charge of the story of my childhood and childlessness; and in order to locate myself, if not within a body then in the narrow space between one letter and the next.<sup>3</sup>

Writing is its own way of healing, if only by giving shape to a life that, while disrupted beyond recognition, is still one’s own. Perhaps that is why Zuckerman’s plan to abandon writing to become a doctor—and arm himself with moral clarity pure enough to render his mortal coil obsolete—fails so spectacularly. The novel ends with him convalescing in a hospital, withdrawing from opioids, and recovering from a drunken accident that has added another layer of physical suffering. Still determined to be a doctor he follows the residents around on their morning rounds, writing questions with his broken jaw wired shut. In the final scene he throws himself into the hospital’s laundry closet and sits there, arms deep in a tangle of soiled hospital linen. He is overwhelmed by the smell and sensation of bodily fluids. “This is life,” he thinks, desperate to return to the reality of a logical universe, where sickness has tangible consequences, where wounds bleed onto fresh linen.<sup>1</sup>

As the final line reminds us, his place in that “real” world is untenable; he belongs to a body following a script of its own. “He still believed he could unchain himself from a future apart and the corpus that was his.”<sup>1</sup>

Hanging over him, and his denial, is the inevitability of a different reality, one yet to be shaped by the character-author but perhaps completed by Roth himself.

### References

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